



## Dear Stacey: What Are My Rights As a Cancer Patient?

**Stacey L. Worthy, Esq.**  
Executive Director  
Aimed Alliance

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**Andrew Schorr:**

Hello and welcome to Patient Power. I'm Andrew Schorr in Carlsbad, California. I am so excited to connect once again with Stacey Worthy in Washington, DC. She's counsel to the Aimed Alliance, which is fighting for laws and enforcement of laws to protect us as we get access to care, the access we need and deserve. Stacey, thanks for being with us.

**Stacey Worthy:**

Thank you for having me.

**Andrew Schorr:**

Stacey, we're kicking off the Dear Stacey series, where we'll do this as an ongoing series to help people where they can write in and raise their questions, not too personal because we can't do law over the Internet, but we can give people some guidance related to the situations they have so they really can defend their rights.

Stacey, I've got a bunch of questions as we kick off the series. Are you ready to go?

**Stacey Worthy:**

I am, yes.

**Andrew Schorr:**

Okay. So first of all, what are some of the main concerns that cancer patients face when it comes to their rights as patients?

**Stacey Worthy:**

I think it's two-fold. One bucket of questions has to do—or issues has to do with insurance and healthcare coverage. So is their health plan going to cover their condition? Are they going to have access to their healthcare providers, their treatment, their medications? Will they be able to afford their treatment or medication? Is there any form of assistance?

And then the other bucket of questions is their rights as an employee. So can they be fired because they have a particular condition? Can they take time off? And what kind of accommodation can they seek? So those are really the two types of issues.

When it comes to coverage what they should be mindful of is selecting a plan that covers their condition. So under the current law we have the Affordable Care Act, which prohibits discrimination based on a pre-existing condition. It requires coverage of essential health benefits, which are several categories of coverage—of benefits such as prescriptions or emergency care or laboratory services.

It also provides a cap on what you have to pay out of pocket. It's around 7,000 for individuals and 14,000 for families. However, not all plans have to comply with this law, and now we're seeing rules that are starting to be enacted—or passed, rather, that would not require plans to follow those laws. So you really have to make sure that when you're entering into a plan you know that it does cover your condition.

And then once you're in that plan there may be limitations that your insurer may place on your treatment or your providers, such as prior authorization, requiring you to get the insurer's approval before you can access your treatment. And prior authorization can lead to delay in care, so it may make you wait anywhere from a day to possibly even a month before they approve access to the treatment. That can be very problematic. You might need that treatment immediately. You might even have to go to the emergency room to get your treatment, because you can't get it through your insurer. So those are things to be aware of.

And then in terms of affordability, you want to make sure your plan covers your treatment because if it doesn't, then you might have to pay out of pocket. Or if you want to see a particular provider, you need to make sure that they're in the network because otherwise if it's an out-of-network provider, you may have to pay more out of pocket. So it's just really important to know what your plan covers.

**Andrew Schorr:**

Wow. So we have another group of interviews we're doing with a woman named Nancy Novack, who has something called Nancy's List, and one of the things that has really struck me about what Nancy said is ask questions up front. If you're diagnosed with cancer, what are the costs involved, and talk to your insurance company to understand a what coverage you have, what are the hoops you have to jump through, and I get that from what you're saying. So these are essential roadblocks that people face, right?

**Stacey Worthy:**

Mm-hmm.

**Andrew Schorr:**

Where the insurance company is saying, well, you got to jump through these hoops to get the cover—the treatment that your doctor is recommending, or it's got to be that other doctor down the street, not the one you've gone to, right?

**Stacey Worthy:**

Yes. So there are several roadblocks that patients with cancer in particular face. And one of them is a called adverse tiering. It's this concept of when you may have a condition such as certain types of cancer where they'll take every medication that treats it and place it in the highest cost specialty tier. So that means that you're paying could be 40, 50 percent co-insurance out of pocket. That's the percentage of what the drug costs. So you might have to pay \$1,000 per month until you meet your maximum or your deductible because of this co-insurance.

And there was a recent study a couple years ago that showed that there was about 80 percent of plans in six different states placed 22 of the most commonly used cancer medications in that highest-cost tier. So when you think about that, it really is a form of discrimination, because it's encouraging the patient not to sign up for that plan knowing that they don't have good coverage of their condition.

Another roadblock, as I mentioned, is prior authorization, and this also comes up a lot with patients with cancer, especially with patients with rare forms of cancer, because a lot of times there aren't FDA-approved treatments. So a practitioner might need to prescribe something off-label, meaning that it's prescribed not according to what the FDA approved it for, but it's still standard of care. However, the insurer may require prior authorization. It may say that it won't cover off-label at all.

In some instances, there's this catch-22 situation of making you try something off-label before you can access something else, but then not covering the off-label treatment, so you're required to pay out of pocket before you can get what your practitioner was trying to prescribe for you. So that's a really bad practice.

Another type of barrier is narrow networks. So this is when the insurer might not have a lot of practitioners for you to see. A lot of patients with cancer might need to see a specialist, and I know some with cancer there's an average of seven physicians you might need to see. You might need to go to an academic cancer center, but insurers may have very few specialists or treatment centers in network.

There's also a recent study that found that 41 percent of Medicare Advantage plans, there were designated cancer centers in the area, but they wouldn't provide coverage in network of those cancer centers, so the patients had to go out of network. And so, of course, they're going to have higher out-of-pocket costs. So it's just—it's not fair, but that's how things are working right now.

**Andrew Schorr:**

So as we have this litany of issues of people trying to get the care they need and deserve and what their doctor and they feel is right for them, who is the right person for a patient to contact regarding issuing related to their coverage?

**Stacey Worthy:**

So there are a few different people that you should talk to. First, your insurer, you want to call your insurer. You can have an informal conversation, find out what's covered. Don't be afraid to ask for a supervisor if you don't get the answer that you're looking for. Sometimes insurer representatives are trained to just say no automatically up front, so keep going until you get more information, and perhaps the next person you talk to might have better information for you.

You also want to talk to your doctor. A lot of times your practitioner will be able to help you navigate the process and help you get approval of your treatment. And if they can't, you can always talk to a patient navigator. This is a person who is trained to assist you with your health insurance plan, with medical decisions, with financial issues, and typically they are employed through a federal grant, so they usually are free of charge. I know the American Cancer Society has a patient navigator program, so they are available to you.

If you can't afford your medication, you can always try contacting your drug maker. Sometimes they have co-payment assistance, so they might be able to help you.

And then if you really think that your insurer is doing something unethical or illegal, you can contact your attorney general or your insurance commissioner.

**Andrew Schorr:**

Okay. That's what I was going to ask is if you feel that you're just getting stymied and you're terrified about your inability to get the care that may be lifesaving or life expanding for you or a loved one, it sounds like then you do go to the authorities. What's your experience? Does that work? I mean, have you seen it, Stacey, where a call to the insurance company's office, that they're responsive and then it can turn things around?

**Stacey Worthy:**

Well, before you can do that you have to exhaust your insurance appeals process. So it can be successful, but you have to take the steps necessary to get to that point. So you're going to want to work with your insurer to appeal the denial first. It might be an informal appeal and then a formal complaint—or appeal, then you go to an independent reviewer, and if at that point you're still denied care, then, yes, you could file a complaint with your insurance commissioner or your attorney general.

And it can be successful, but I've heard that it's more successful the more people who complain. So if you know that you're not the only one who is being denied access, you know other people in the same situation as you, you want to get everybody to file a complaint. So the larger the volumes the better chance that they're going to respond.

And sometimes the more efficient way to do things is to call a reporter, speak to the media, because the insurer does want that publicity, they don't want bad press, and if they're denying access to a lifesaving treatment or provider or service that's going to possibly make the news, and they're going to act pretty quickly.

**Andrew Schorr:**

Right. Good point. And having been a reporter for a long time, right. Those are very powerful stories and can make things move quickly. So could you just tell us the goal of the Aired Alliance?

**Stacey Worthy:**

Yeah. So actually we don't lobby. We're a 501(c)(3), but we do strategize and figure out ways in which we could improve access through law. So we'll identify areas where there are deficiencies, where patients can't access their treatment or come up with ideas for how they can be improved, and then we'll work with other nonprofit patient advocacy groups, so that they can approach lawmakers if necessary.

Another thing that we do is to try to encourage insurers or employers to fix their policies with them even without going through that legal route. So if we know that a particular insurer is discriminating against a patient or they have a policy that might result in adverse health events, then we try and work with them to encourage them to proactively change what they're doing and really look to the best interest of the patient.

**Andrew Schorr:**

Wow. Well, good for you, Stacey, and Patient Power will certainly ever work more closely with Aired Alliance. So for those of us who are affected in this way, write in, [dearstacey@patientpower.info](mailto:dearstacey@patientpower.info). Look for our ongoing series where we'll be tackling your questions and sort of globalizing the answers to help the most people. And if you have these horror stories sometimes, tell us about them, and we certainly will forward them to Stacey to see if the Aired Alliance can help make changes.

Stacey Worthy, thank you so much for being with us. We're really excited about the ongoing Dear Stacey series and really helping people get the care they need and deserve. Thanks for being with us, Stacey.

**Stacey Worthy:**

Thanks for having me.

**Andrew Schorr:**

I'm Andrew Schorr with Patient Power. Look for us many times, Andrew here in California and Stacey, healthcare attorney with the Aired Alliance in Washington, DC. Remember, knowledge and fighting these access issues can be the best medicine of all.

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